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CHAPTER 6

Transitioning People from Institutions to the Community¹

The realization that many people with long-term care and support needs can thrive in integrated community settings has led to an increased commitment to transition people from ICFs/MR, nursing homes, and other long-term care institutions to the community. Since such persons have widely varying needs, the transition process presupposes that a wide range of community services and supports are in place or under development. Approaches and methods for developing the infrastructure needed to support community living are discussed in other chapters of the Primer. This chapter begins with a brief overview of how states have used Medicaid HCBS waiver programs to transition persons from ICFs/MR to the community. It then discusses (a) important factors states need to consider when planning transition programs for persons in nursing homes and (b) options for using Medicaid dollars to help cover certain transitional costs.

Introduction

Many states have been active in creating alternatives to institutional care for persons with disabilities, in order to provide services and supports in the most integrated setting appropriate to an individual's needs. The recent Supreme Court decision (Olmstead v. L.C.) gives legal weight to this policy direction.² State efforts to move persons out of nursing homes and other long-term care institutions into community settings can be an important part of a state's "comprehensive effectively working plan" for providing services to qualified persons in the most integrated setting, as described in HCFA guidance sent to states in January 2000. (See Appendix II for the complete text of this guidance.)

Transitioning people with disabilities from institutions to the community began in a serious way with the recognition that many persons with mental retardation and other developmental disabilities were living in large public institutions for whom institutional placement was not, in fact, appropriate. This recognition, starting in the 1970s, led to successful efforts by many states to sharply reduce the number of people living in large institutions (16 or more beds) by transitioning residents to a range of smaller, community settings. This dramatic wave of deinstitutionalization set in motion the realignment of state developmental disabilities service systems from institutionally dominated to community-centered systems.

The first section of this chapter provides a brief overview of the transition experience from ICFs/MR, distilling the lessons learned from the experience that apply to transition programs more generally. The chapter then discusses major factors states need to consider when setting up transition programs, focusing primarily on the transition of nursing home residents.

Lessons from the Transitioning Experience with ICFs/MR³

Medicaid funding for home and community services for persons with mental retardation and other developmental disabilities, particularly through HCBS waiver programs, has played a pivotal role in enabling a substantial majority of states to reduce (or in some cases, end completely) longterm care service delivery in large state institutions. Between 1992 and 1999, states closed more than 80 large public institutions. Eight states and the District of Columbia no longer have any large state institutions in operation. The number of individuals served in non-state ICFs/MR in these and other states has also declined, as states have shifted to using HCBS waiver programs as a means to pay for home and community services for people with developmental disabilities.

When HCBS waiver programs became available, many states (e.g., Colorado, Oregon, Vermont, New Hampshire) ceased sponsoring additional ICF/MR development altogether. For example, while closing the Laconia state institution in 1984, New Hampshire switched entirely to providing HCB waiver services to both former residents and individuals with similar needs already in the community.

The decline in ICF/MR utilization began about the same time that the number of people with developmental disabilities participating in HCBS waiver programs began to grow very rapidly. Between 1990 and 1999, the number of individuals participating in HCBS waiver programs for people with developmental disabilities grew nearly sixfold.⁴ A major reason for increased use of HCBS waivers is the flexibility they afford states to offer services and supports that can accommodate individuals with a wide range of different needs in a targeted fashion without resorting to institutionalization (discussed further below).

The successful transitioning of people with developmental disabilities from institutions to the community demonstrates that HCBS services can be cost-effective substitutes for institutional services. However, the mere exchange of one source of funding for another is not the whole story. States that have been especially successful in closing

large public facilities and reducing reliance on institutional and ICF/MR services overall have taken many other important steps to ensure that the needs of individuals with developmental disabilities could be met in the home and community. Many of these steps are equally applicable to beneficiaries with other disabilities being transitioned from nursing homes, state mental hospitals, and other institutions (as discussed further in the next section).

- Development of community-based crisis and quick-response capabilities. Maine established crisis response teams, resource coordinators, and emergency placement beds in small settings in each of its three regions as part of the initiative to close its Pineland Center facility. Pineland Center had functioned as a "crisis-placement" facility. By providing resources in the community to respond to crises and working out permanent solutions for the individual, a prime rationale for operating Pineland was eliminated. Development of a similar capability was instrumental in Vermont's closing its Brandon facility in 1992 and in Oregon's closing its Fairview facility in February 2000.
- Being prepared to meet, in the community, the needs of individuals with multiple disabilities who need particularly intensive services. Individuals are often portrayed as "requiring" institutional services, when they can actually remain successfully in home and community settings as long as they have relatively intensive supports. The need for such intensive services may continue indefinitely for some of these individuals. For others, a decrease in service intensity over time has been noted. States have taken steps to provide the needed services in a community setting by permitting development of HCBS waiver plans of care that allow costs above the average for institutions in that state. This allows states to decide on the plausibility of transitioning for a particular individual, without forcing individuals de facto to seek institutional care simply because of a cost cap.
- Provision of higher than average funding allocations for individuals transitioning to the community.
 States have found that the costs of community services for people being transitioned from

institutional services can be higher than the costs of HCB waiver services furnished to persons who have not been institutionalized. This cost differential arises in part because many institutionalized persons have multiple functional limitations that require more intensive service provision to enable them to remain in the community. But the main reason for higher costs is that such individuals tend to require more paid services simply because they frequently lack adequate networks of informal and community supports (a lack that led to their institutionalization in the first place).

Although most states accommodate transitioning individuals from institutional settings through their existing HCBS waiver programs, a limited number operate distinct HCBS waiver programs for people transitioning from institutional settings. For example, Georgia created a special HCBS waiver program for individuals who transitioned to the community during the state's closure of its 320-bed, Atlanta-based Brook Run facility in 1997. Closure of this facility resulted in cost savings that enabled Georgia to provide HCB waiver services to 180 additional individuals over and above the persons placed from institutional settings.

- Development of family support programs. Family support services are crucial in avoiding unnecessary placements and are used by many states to reduce reliance on institutional services. For example, Michigan reduced the number of individuals it served in large public facilities from over 6000 in 1977 to fewer than 300 in 1998—in large part by launching and sustaining family support programs.
- Development of strong, locally centered community service systems. In developmental disabilities services, creating a strong infrastructure at the community level has proven important in avoiding institutionalization and promoting quality service. Development of New Hampshire's locality-based, non-profit Area Agency system played a major role in facilitating closure of its Laconia facility. An important step in Michigan's transition activities was the state's strengthening of its network of local

governmental Community Mental Health Service Programs. As part of its overall plan to close its Brandon facility, Vermont placed major emphasis on upgrading the skills of its community workforce and maintains a strong program of training community workers. In Kansas, the state developmental disabilities authority and the state's University Affiliated Program forged a partnership to improve the training and skills of the community workforce—a step that was instrumental in enabling the state to transition many institutional residents to the community.

Making large-scale investments in quality assurance and quality improvement capabilities. Wyoming used such an investment to successfully place more than two-thirds of all the residents of its State Home and Training School in the community during the 1990s. The Division of Developmental Disabilities outstationed a cadre of field staff-initiating a comprehensive program of top-to-bottom reviews of community programs (including highlighting best practices), among other steps to improve worker training.

General Factors to Consider

Although states have much less experience transitioning people out of nursing homes than out of ICFs/MR, the earlier experiences transitioning persons with mental retardation and other developmental disabilities to the community provide valuable lessons for transitioning residents of nursing homes; and the same principles apply. The ability to achieve successful transitions from institutional to community-based living depends fundamentally on the ability to match the needs of the persons who have been living in nursing homes or other institutional environments with the availability of home and community services to meet those needs.

Persons leaving ICFs/MR have varying types and levels of need. Residents of nursing homes or other types of institutions are an even more heterogeneous group. In the same nursing home, for example, the individuals to be transitioned may

Nursing Home Transition Grants Program

To assist states in providing transition options to Medicaid beneficiaries residing in nursing homes, HHS-through the combined efforts of HCFA and ASPE—has sponsored a grant program entitled the "Nursing Home Transition Program." Its purpose is to assist current nursing home residents who choose to do so to move to home and community settings, remain there safely, and maximize their participation in community life. In 1998, grants averaging \$175,000 were made to four states: Colorado, Michigan, Rhode Island, and Texas. In 1999, grants averaging \$500,000 were made to four additional states: New Jersey, New Hampshire, Vermont, and Wisconsin. Each of the grantee states has implemented transition programs unique to their long-term care systems. HHS plans to continue making grants under this program for one additional year and perhaps longer. The 1999 Supreme Court decision in the Olmstead case, which requires states to develop plans for serving persons with disabilities in the community, has increased state interest in the program.

include a 75-year-old with cognitive impairment and multiple medical problems, a 45-year-old with quadriplegia, and a 25-year-old with a traumatic brain injury. They will have some needs in common. But they will also require services and supports tailored to their specific situations.

Whether a person currently resides in a nursing facility or an institutional facility the state is down-sizing or closing, the steps in planning or arranging for community services are the same. In either case solid transitional planning is essential. However, additional challenges are involved when downsizing or closing an institutional facility, including maintaining the quality of facility services and worker morale, assisting workers to find other employment, addressing the "dual funding" problem (i.e., meeting the costs of maintaining facility operations while underwriting the costs of community placement), and ensuring that any special services provided in the facility will be available to individuals after they have left the institution.

Because each person has unique needs, the complexity and cost of an individual's actual transition process will vary. For this reason, it is crucial that transition programs be designed to operate with maximum flexibility. However, seven over-

arching steps need to be taken in setting up all transition programs, irrespective of the particular needs being addressed:

- Identifying and addressing administrative and legal barriers
- Identifying and educating residents with the desire and the potential for transition
- Involving and collaborating with key players in the disability arena
- Developing and implementing care management systems that support transition
- Identifying and addressing housing needs and payment sources
- Providing innovative and flexible funding mechanisms
- Establishing a quality assurance system that effectively balances risk and autonomy.

The remainder of this chapter discusses these activities as they relate to the transition of nursing home residents to the community. It is important to note that, although Medicaid can be used to help support many of these activities, states that have undertaken transition programs or facility closures emphasize that many costs associated with them are not covered by Medicaid. Such costs can include temporary rental assistance, furniture and clothing, and direct cash payments to individuals and families for one-time costs associated with the move.

Identifying and Addressing Administrative and Legal Barriers

The first step a state must take when considering whether to start a transition program is to analyze state Medicaid regulations and administrative policies. This is to identify any institutional bias that might make it difficult or impossible for some people living in nursing homes to be served in the community. If a state does not use the 300 percent special income rule for its HCBS waiver program, for example, some nursing home residents will

not meet the financial eligibility criteria for waiver services, even though they can be appropriately served in the community. Similarly, if Medicaid's maintenance needs allowance is too low to permit the person to cover realistic room and board costs in the community, persons living in nursing homes may be unable, simply for financial reasons, to transition to certain residential care facilities. (See Chapter 2 and Chapter 5 for indepth discussions of such barriers.)

Identifying and Educating Residents with **Desire and Potential for Transition**

Medicaid flexibility gives states the means to develop home and community programs able to serve individuals with widely varying needs. States, however, face a number of challenges when developing a successful nursing home transition program. They must first establish who the target population will be: Individuals under age 60? Those with a lower level of need (versus those needing a skilled level of care)? Those who have been in a nursing home for less than a year?

Once the target population has been selected, states must then develop referral, screening, and assessment procedures to identify individuals residing in nursing homes (or other institutions) who have the desire and the potential to be transitioned successfully to the community. Some states have used the nursing home minimum data set (MDS)⁵ or other screening and assessment tools as a baseline to identify potential candidates. The MDS is a core set of screening and assessment elements that forms the foundation of the comprehensive assessment for residents of long-term care facilities. By looking at factors captured in these data sets—such as medical needs, functional status, and lengths of stay-transition programs can screen for potential candidates, who can then be further assessed for transition. The MDS data also include limited information on consumer preferences, which states might find useful to review in their initial screen as well.

Using MDS data in this manner, while a useful step, is by no means sufficient. Many individuals who are good candidates for a transition program may not show up in the initial screening. Therefore, programs should not rely solely on screening tools but should work with persons and groups who know the nursing home residents, as well as the services and supports that may be available to them. Such knowledge can make them invaluable sources of information to identify appropriate candidates for the program. Nursing home ombudsmen, independent living centers, protection and advocacy organizations, and other local groups and programs can also serve as important partners in the identification process itself. A number of states use centers for independent living to assist in the identification of

Examples of State Transitioning Programs

Maine

The Alpha One Center for Independent Living in Maine instituted a state demonstration program in 1997 to move 40 adults under age 60 out of nursing homes. An independent evaluator is currently using the MDS database to profile and track individuals who leave the nursing home* and compare their characteristics with those of a similar population that remains in the nursing home.

The demonstration will track and compare functional status and quality of life changes. The results will yield a profile of required supports for successful community living. Another component of the evaluation will determine policy problems in the state that create barriers to community living.

Vermont

As part of its "One to One" transition program, Vermont has developed an assessment instrument, using a formula derived from the MDS to profile those individuals with a high potential for success in the community. Individuals are targeted for transition based on this assessment, their resource utilization groups (RUGs) classification, and other factors, including preference for community placement.

*For the individuals who leave the nursing home a modified MDS must be used, because the MDS itself is used only in an institutional context.

individuals and with the transition process. The expertise and capabilities of such community organizations should be tapped early on to assure effective collaboration. Finally, individuals for whom a successful transition plan could not be arranged during the initial attempt should be recontacted on a regular basis to discuss new options for achieving the transition goal.

Involving and Collaborating with Key Players

To develop processes and procedures that will result in the successful relocation of nursing home residents who are appropriate for home and community settings, states need to take account of the interests of multiple constituents. Nursing facilities have business interests to protect; legislators have budgets and constituents to consider; communities and community providers have capacity constraints; families and other potential caregivers may have multiple competing responsibilities.

A good way of taking these interests into account, and thus increasing a nursing home transition program's chance of success, is to develop partnerships with these key constituents. Partnerships can be with the consumer, the consumer's family and significant others, advocacy groups, Centers for Independent Living, housing authorities, other state agencies, the state legislature, and the nursing homes themselves. Some of these entities can also assist the state Medicaid program to identify the home and community service infrastructure necessary for a successful transition and help design service and support systems. It is important that the key constituent list include individuals or groups that are experienced in moving people out of nursing facilities and that they be involved at the earliest feasible point in the process.

Advocacy groups and consumers can be used to educate case managers about the consumer's needs and preferences. Nursing homes can be another valuable resource, and many welcome assistance with discharge planning. Nursing home social workers, for example, can work with residents and family members to identify necessary medical and other supports (therapists, physicians, mental health centers) and provide

charts, MDS assessments, and plans of care. Nursing home staff can also help to identify candidates for transition.

Developing and Implementing Care Management Systems That Support Transition

Care management—also called case management and service coordination—is the process of using information from an assessment to develop a service plan. It involves working with a client (and family when appropriate) to identify the client's goals, preferences, and priorities, and to draw up a plan to provide the services necessary to support the client in the community. Care management also includes arranging for services, following up to ensure that services are in place, developing networks of individuals and organizations that can provide ongoing support, monitoring the client's situation on an ongoing basis, and adjusting the service package as needed.

Strong and flexible care management is central to the success of a transition program. Intensive care management systems can successfully relocate individuals into the community, often with long-term cost-savings. Medicaid allows states to pay for care management services related to transitioning an individual from an institution, as long as they do not duplicate regular discharge planning services paid for through another source. Medicaid-reimbursable care management services that help to ensure a successful transition include:

- Discussing options with the resident
- Arranging visits to potential settings
- Providing consumer education and training prior to discharge
- Arranging transportation on moving day
- Making sure the new location is appropriately furnished
- Implementing a plan of care so that services are available immediately when the beneficiary moves.

Colorado's Deinstitutionalization Pilot Project

A single entry point (SEP) program integrates multiple providers in a system that delivers long-term care services to persons with a wide range of conditions and service needs in a way that appears seamless to the clients. Colorado has expanded the role of its SEP program to provide case management services to residents in nursing facilities who can and choose to be supported in community settings. The SEP program was established in 1993 to provide integrated referral and assessment of potential clients for the state's HCBS waiver and state-only community care programs. Under the pilot program, the Colorado Department of Health Care Policy and Financing and the SEP program worked closely with nursing homes to identify potential clients. The state evaluated the transition program's cost and processes and measured client pre- and post-transition satisfaction.

The evaluation found that nursing home staff were the most frequent source of referrals and a critical resource for identifying candidates for successful transition. Factors associated with successful transitions included the availability of family support and the use of case management services. Age and functional limitations did not appear to be significant determinants of a successful transition. Most successful transitions occurred for those individuals residing in the nursing facility for less than one year. (See Chapter 9 for an in-depth discussion of SEP systems.)⁶

Three options are available for obtaining Medicaid reimbursement for care management services: case management as a waiver service, the targeted case management option, and administrative claiming.⁷ (Chapter 5 describes in detail the advantages and drawbacks of each of these payment methods.)

The targeted case management option is likely to offer the most flexibility, because it can be targeted specifically to persons who are being transitioned to home and community settings. The Federal statute defines targeted case management as "services which assist an individual eligible under the plan in gaining access to needed medical, social, educational, and other services." This definition enables states to coordinate a broad range of activities and services outside the Medicaid program that are necessary for the optimal functioning of a Medicaid beneficiary. States desiring to provide these case management services under the targeted case management option may do so by amending their state plans accordingly. If a state does not plan to offer the service to all Medicaid recipients, the amendment must specify precisely the group or groups to be served.

HCFA recently enacted a policy change making it possible to obtain Medicaid funding for case management services provided during the last 180 consecutive days of a Medicaid-eligible person's institutional stay, if provided for the purpose of community transition. When the case management services are provided under the targeted case

management option, states may specify a shorter time period or other conditions under which targeted case management may be provided.⁸

Case management furnished as a service under an HCBS waiver may also be provided to institution-alized persons during the last 180 consecutive days prior to discharge. However, FFP is available only on the date the person leaves the institution and is enrolled in the waiver. In these cases, the cumulative total amount paid is claimed as a special single unit of transitional case management. See Appendix II for the complete text of the recent case management policy changes.

Identifying and Addressing Housing Needs and Payment Sources

Lack of accessible, appropriate, affordable, and safe housing can be a major barrier for transition programs. Waiting lists for support services often run up against even longer waiting lists for housing. In some cases, individuals may remain in nursing homes solely because there are no other housing alternatives. In such cases nursing homes could essentially become shelters for homeless people.

Housing needs differ, depending on individual needs. States have been working with their regional and local housing authorities with varying degrees of success to come up with creative solutions to housing problems. Stronger partnerships between health and housing authorities at both the state and Federal levels are often cited as the most important need in the search for comprehensive approaches to maintaining people in the community.

Many states have chosen to offer assisted living, generally to persons age 65 and older. This term refers to a combination of housing and services in a residential environment that serves to maximize the autonomy and functioning of residents, many of whom require assistance to pursue their day-to-day activities. States do this by combining housing dollars from various sources (e.g., state, Federal, and private funds) with service dollars from Medicaid's HCBS waiver program or, to a lesser extent, through the Medicaid state plan personal care option.

In FY 2000, the U.S. Department of Housing and Urban Development (HUD) was authorized to offer funding to develop and/or convert Section 202 housing stock to assisted living facilities. HUD will provide subsidies to providers based on an approved state or local plan to furnish appropriate supportive services. Some analysts believe that conversion of Section 202 housing to assisted living has the potential to support a consumerfocused model, by organizing services around the resident rather than a facility. Others argue the reverse—that these opportunities can limit individual autonomy by tying housing to services. These observers would rather see housing and service dollars following people to their settings of choice. In any case, pairing HUD and Medicaid dollars to provide assisted living does provide certain low-income persons—particularly frail elderly persons—with an affordable alternative to nursing homes. (See Chapter 5 for a detailed discussion of factors to consider when using Medicaid to cover assisted living for older persons.)

Assessments for accessibility

Environmental modifications are often crucial to a state's ability to serve an individual in the community. FFP may be available for the costs of assessing accessibility and the need for modifications in a person's home or vehicle in three ways.

First, FFP may be claimed at the administrative rate for assessments to determine whether the person's home or vehicle requires modifications to ensure the health and welfare of an HCBS waiver participant. (Assessment costs incurred to determine whether an individual's needs can be met under an HCBS waiver may qualify for FFP regardless of whether or not the person is eventually served under the waiver.)

Second, the cost of environmental assessment may be included in the cost of environmental modifications under an HCBS waiver. Third, the assessment may be performed by another service provider, such as a home health agency or an occupational therapist. FFP is available at the service match rate when these providers perform assessment in addition to their other duties. (See Appendix II for the complete text of HCFA's guidance on FFP for assessing accessibility.)

Providing Innovative and Flexible Funding Mechanisms

One potential barrier to a successful transition program is inflexible funding streams. Even when home and community services are less expensive than nursing home care, it is often difficult for an individual to choose these services due to either one-time costs associated with transitioning or lack of coordinated funding. Typical one-time costs associated with moving into a community home include: first and last month's rent, security deposit, telephone deposit and installation fees, bed, linens and towels, and cooking utensils. Such costs will vary due to geographic differences in rents. One estimate puts them in the range of \$1800.9

Transition programs need flexible funding arrangements that permit funding to shift from institutional care to home and community services by following individuals to the service setting of their choice. Oregon's regulations, for example, use state-only dollars to provide a special needs allowance for beneficiaries who are being diverted from entering or relocated from a nursing facility. Under this provision, payment for one-time needs can be authorized for household equipment and furniture, minor home repairs, rent or utility deposits, moving costs, property taxes, and transportation costs. Such special needs payments can be authorized only after all other sources of sup-

port (e.g., family, neighbors, friends, United Way, Salvation Army) have been utilized.

Establishing a Quality Assurance System That Effectively Balances Risk and Autonomy

Community living presents a different set of risks from those associated with living in an institution. Transition programs need to have a quality assurance (QA) system that monitors and helps ensure service quality and client safety, particularly for the first few months in the community setting. At the same time, however, such a QA system must respect individuals' autonomy by acknowledging their choice to assume risk. The balance is delicate and can be hard to achieve. Programs that use a consumer-directed model allow individuals to assume more individual responsibility and accountability in a residential care setting than does an agency-directed model (see Chapter 7 for a full discussion).

The assurances HCFA requires from states for approval of HCB waiver services include "necessary safeguards" to protect the "health and welfare" of persons receiving services in the community. Since HCBS waiver programs serve a diverse array of target populations, no one-size-fits-all application of these QA requirements can be prescribed. (Further discussion of quality assurance and improvement is outside the scope of this Primer.)

Obstacles to Look For

Although transitioning people out of institutions can save money over the long term, the process can incur major up-front costs that are not reimbursable by Medicaid. Given this, states may want to consider strategies that will divert people from entering institutions, particularly nursing homes, in the first place and ensure a quick return to the community if placement is unavoidable.

The ICFs/MR experience illustrates that the best transition program is one that makes sure that very few people will need to be transitioned. In

Hawaii's System for Transitioning People with Serious Mental Illness to the Community

In response to a Federal court consent decree, the Hawaii Department of Health, Adult Mental Health Division developed a program to identify persons residing in Hawaii State Hospitals who could more appropriately be served in the community. Each patient was assessed by clinical staff at the hospital and a discharge plan was developed for those so identified. These discharge plans were also used to develop a community service plan, which includes a variety of clinical, residential, and support services. State funds were used to develop new services, including case management, assertive community treatment, and housing. Medicaid funding pays for many of the services, but not for housing. As a result of this program, between 1997 and 1999 the state experienced an approximately 34 percent increase in discharges from the State Hospital.

the mental retardation and developmental disabilities field, this is known as the front door/back door connection. Little progress with transitioning can be made so long as the front door to the institution remains open; intervention before inappropriate placement (i.e., diversion) is easier than intervention after placement.

Many persons who can be served successfully in the community are admitted to nursing homes from hospitals. In some cases, this may be because hospital social work staff, under pressure to discharge people quickly, may not be aware of or have the time to explore community options. As part of their approaches to expanding community placement strategies, Colorado and Texas have developed procedures specifically to divert appropriate individuals from nursing home placement after a hospital stay.10

Colorado's program serves as an example. Colorado developed its diversion program to address state-specific barriers to community placement. These included: (a) long delays in processing Medicaid eligibility prior to discharge from hospitals; (b) lack of general awareness of community options on the part of discharge planners and consumers; and (c) inadequate personal resources to stay in the community.

To respond to the first of these obstacles, Colorado instituted a hospital-based care management program that dispatches a special case manager to a pilot site hospital (both inpatient and outpatient settings) solely for the purpose of ensuring an expedited Medicaid eligibility determination process. The program is now in the process of developing a screening instrument to identify persons at risk of nursing facility placement, for use by hospital discharge planners and case managers. (Chapter 9 discusses ways to expedite eligibility determinations.)

Endnotes

- 1. The primary contributors to this chapter are Gavin Kennedy, Gary Smith, and Janet O'Keeffe.
- 2. The Court affirmed the rights of qualified individuals with disabilities to receive services in the most integrated settings appropriate to their needs. Under the Court's decision, states are required in specific circumstances to provide community services for persons with disabilities who would otherwise be entitled to institutional services. See Introduction for more information on the Olmstead decision.
- 3. The information in this section is drawn from the following sources: Prouty, R., and Lakin, K.C. (2000). Residential services for persons with developmental disabilities: Status and trends through 1999. Minneapolis, MN: University of Minnesota, Research and Training Center on Community Living. Smith, G. (2000). Medicaid long term services for people with developmental disabilities. Alexandria, VA: National Association of State Directors of Developmental Disabilities Services, Inc.
- 4. Smith, G. (2000). *Medicaid long term services for people with developmental disabilities*. Alexandria, VA: National Association of State Directors of Developmental Disabilities Services. Inc.
- 5. Federal law mandates use of the MDS for all residents of facilities that are certified to participate in Medicare or Medicaid SNFs and hospital-based skilled nursing units. These facilities are required to conduct comprehensive, accurate, standardized, and reproducible assessments of each resident's functional capacity using a Resident Assessment Instrument (RAI). The RAI consists of the MDS, Resident Assessment Protocols (RAPs), and Triggers.

- 6. Bell, J. (1998). *The deinstitutionalization pilot project: Evaluation and status report.* Denver: Colorado Department of Health Care Policy and Financing.
- 7. Case management can also be provided as an integral and inseparable part of another covered service.
- 8. Medicaid funding is not available for targeted case management services provided to persons who are receiving services in an institution for mental disease (IMD), except for services provided to elderly individuals and children under the age of 21 who are receiving inpatient services.
- 9. Mike Oxford, Executive Director, Topeka Independent Living Resource Center, Topeka, Kansas. Personal communication. May 23, 2000.
- 10. The states funded these programs in part from a grant through the Nursing Home Transition Program highlighted earlier in the chapter.

Annotated Bibliography

O'Day, B. (1999). Independence and transition to community living: The role of the independent living center. Houston, TX: Independent Living Research Utilization (ILRU) Research and Training Center on Independent Living at The Institute of Rehabilitation and Research (TIRR). (101 pages)

This report discusses the need for community-based and transitional services. It discusses barriers to independent living, highlights centers with innovative programs, and offers policy recommendations. It also provides a brief overview of court cases and legislation affecting people with disabilities (including the Omnibus Budget Reconciliation Act of 1987, and the Americans with Disabilities Act). There is a discussion of ILRU's project to examine "state of the art" transitional services to support community entry for people with disabilities. The project offers information and technical assistance for providing transitional services effectively. Contact information for consultants is also provided. This article may be obtained free of charge on-line at http://www.ilru.org/NewsStand/oday, or contact: ILRU Program, 2323 South Shepherd, Suite 1000, Houston, TX 77019, phone: (713) 520-0232 [voice], (713) 520-5136 [TDD], (713)-520-5785 [fax].